

# Follow up care: supporting patients following head and neck cancers

Sonja Hoy

Clinical Nurse Specialist,  
Head, Neck and Thyroid

The Royal Marsden



# How do we as health professionals support our patients beyond treatment?

“...the cancer experience does not end  
when treatment ends.”

Rowland & Ganz, 2011, p.170



# Acute and Late effects

How long are side effects expected to last and when are 'we' likely to see people start to recover?

Acute recovery post treatment up to 3 months

Delayed recovery 3-6 months

Late effects: after 6 months



## Physical impact post treatment up to 3 months

- Pain
- Oral mucositis, taste changes, difficult secretions
- Alteration to voice
- Swallowing difficulties
- Airway management
- Chronic Fatigue
- Fluid and food causing physical pain and trauma
- Altered hydration and nutrition
- Skin changes: dry or moist desquamation
- Altered body image



P.K 2009

...the weight loss becomes frightening, you are literally a shadow of your self

... then you have to find a way of purchasing clothes....

all on a budget of less than £63.00 pounds a week



## Psychological Care at end of treatment and in the weeks after treatment

- Individuals report side effects worse than the disease
- Ongoing side effects remind patient of enormity of the disease
- Fear of the unknown
- Depression
- Alienation
- Isolation versus socialisation
- Impact on intimacy and sexual well-being



*The* ROYAL MARSDEN

NHS Foundation Trust

Diamond 1999

'..it would not have been so bad if all my taste buds had been pulverised by the rays; but a few held on twitching in their agony and a slight memory of what taste had been like...

and surprised and depressed every time I ate to discovery that food tasted of rancid wall-paper paste.'



**NHS**

## Social Impact:

Started during treatment but can progressively get worse at end of treatment and in the acute post treatment phase

Food and hydration are an essential part of existence and often linked with enjoyment, part of an individuals quality of life

Sharing a meal or drink part of socialising

- Issues arise when patients are not able to engage in what is seen as everyday activities of living
- Fear around visual appearances
- Oral mucositis and tenacious secretions can have a profound impact on communication and socialisation



# Potential issues 3-6 months post treatment

- Lymphoedema
- Psychological morbidity associated with guilt related to diagnosis
- Loss of saliva and impact on eating, drinking and communicating
- Fear of eating in a public place and how to re-engaging in the art of eating
- Facial alterations dependent on treatment interventions
- Trismus
- Swallowing difficulties



## Main issues after 6 months

- Body image, worse if continues to have long term side effects of treatment
- Life long facial camouflage issues
- Fatigue and fertility
- Sexuality and intimacy
- Airway alteration and management
- Financial issues, work, travel and insurance
- Integration back into social networks
- Living and surviving with a cancer diagnosis



# Changing the focus after treatment

As cancer joins the ranks of chronic disease, health care professionals will increasingly find themselves at a juncture with patients, as interest moves away from acute care to managing long-term health

GP's and Oncologists are among the most powerful catalysts for promoting behaviour change and may be optimally positioned to deliver guidance regarding health promotion.

Yet current reports suggest about 20% of oncology care physicians provide assistance in this area. WHY?

**We need to consider alternatives within the wider multi-professional team how to support this specific patient group**



## Especially when

“A substantial number of reports suggest that cancer survivors spontaneously adopt lifestyle changes in the hope of achieving improved health...”

And

“ ...some health behaviours, such as exercise are consistently associated with positive effects on psychological or emotional well-being (mood, self-esteem and QOL) and reduction in fatigue.”

(McBride et al 2000)



however...

“ Although a substantial proportion of cancer survivors spontaneously initiate positive behavioural changes, many do not.

Males and those who are less educated, over the age of 65, or who live in urban areas are less likely to either undertake healthful changes in behaviour or maintain them.”



# What can we do in the post treatment phase?

- Robust Communication methods, knowing how to contact each other, when and how often?
- Understanding who is who across primary, secondary and tertiary care

## Specific Screening points for Head and Neck:

- Consideration of HAD scales to identify at risk patients?
- Utilising Holistic Needs Assessments at specific time points to identify unmet needs acute and /or delayed
- Seamless pathways from Hospital focus care to a community focus
- Post treatment programmes which are tailored to the Head and Neck population that are multi-professional and aimed at recovery and rehabilitation which weaves with the survivorship agenda



# Survivorship is ..

‘a process which began at diagnosis, involves uncertainty, is life changing with positive and negative aspects. It remains an individual experience with universality’

Doyle, 2008



# The Main Survivorship elements

1. Support through primary treatment from point of diagnosis (responsibility for ALL)
2. Promoting recovery
3. Sustaining recovery
4. Reducing the burden of consequences of treatment
5. Supporting patients with active and advanced disease – interfacing with end of life care services



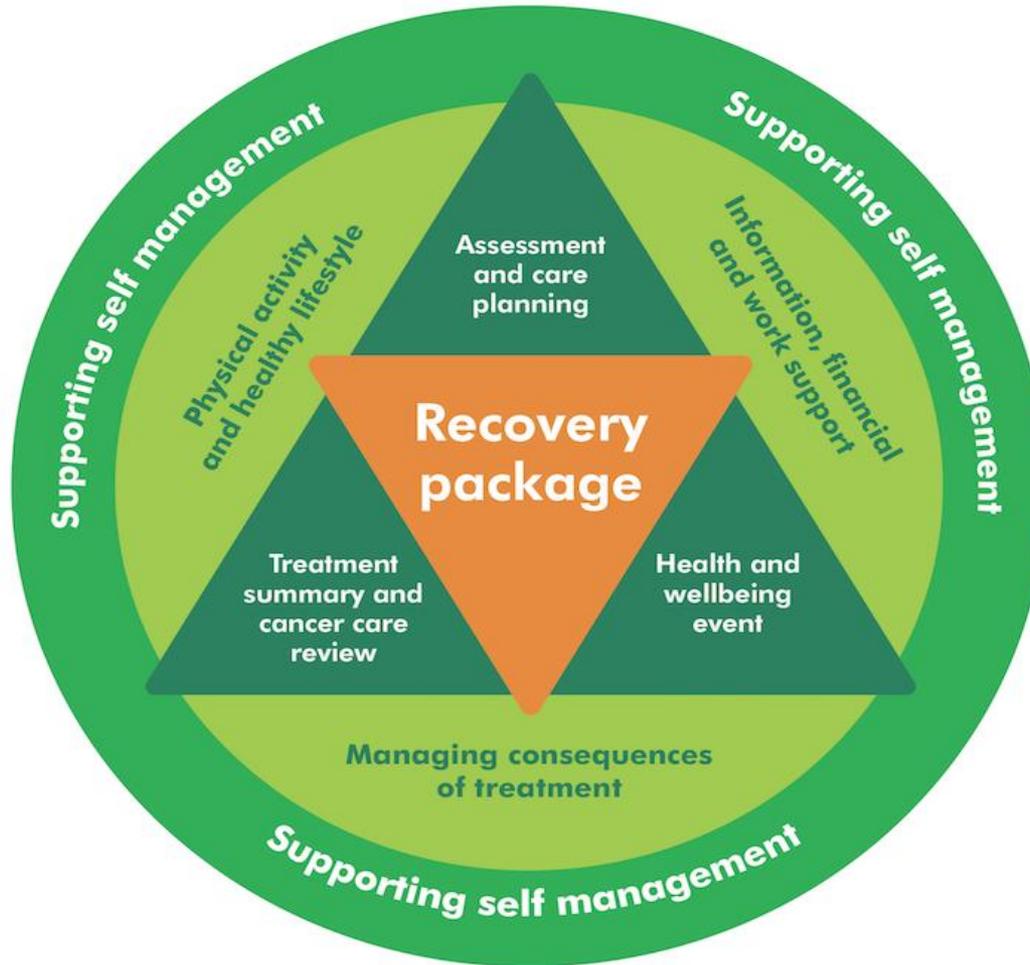
# The Recovery Package

**A series of key interventions which, when delivered together, can greatly Improve outcomes for people living with and beyond cancer.**

- an assessment of holistic needs and the development of a care plan to address these issues;
- a treatment summary that explains to the GP and individual what treatment has taken place;
- a cancer care review by the GP within 6 months of diagnosis;
- and a health and wellbeing educational event.

**By creating a partnership with the individual, the focus of care remains on supporting self-management after a cancer diagnosis.**

# The Recovery Package



Self management approaches that empower and activate people to feel confident about managing their condition

‘Activating’ people so that they can use information and support to manage their health and alter behaviours

Re/skill/train clinicians to take a supportive ‘power sharing’ approach rather than a ‘power holding’ approach.



## In Summary

- An awareness of the post treatment side effects and how to manage them outside a hospital setting
- Provision and access to various HCP dependent on needs
- Improving communication between primary and secondary care
- Is there creative uses for finite resources . Post treatment multi-professional clinics
- Follow-up clinics to identify unmet needs and long term side effects with a focus of rehabilitation
- As an MDT, starting to map or identify key Survivorship issues within Head and Neck to help shape the direction of treatments, care and services specific to the long term morbidity issues
- Ongoing Research and audit
- Using the voice of the whole MDT and patients to help 'us' start to re-shape services that are focused on recovery and living beyond a cancer diagnosis

